



Meeting Minutes

Meeting of the Rare Disease Advisory Council (RDAC) Academic Research Institutions Subcommittee

Date: Tuesday, January 23, 2024

Time: 12:00 PM – 1:00 PM EST

Microsoft Teams Video Conference

Academic Research Institutions Subcommittee:

Member Name	Member Seat	Present	Absent
Representative Adam Anderson	An individual who is a caregiver of an individual with a rare disease.	X	
Dr. Barry Byrne	A representative from an academic research institution in Florida, which receives grant funding for research regarding rare diseases.	X	
Dr. Divya Patel	A physician who is licensed under Ch. 458 or 459, F.S., practices in this state, and has experience in treating rare diseases.		X
Dr. Mustafa Tekin	A representative from an academic research institution in this state which receives grant funding for research regarding rare diseases.	X	
Dr. Rajan Wadhawan	A physician who is licensed under chapter 458 or chapter 459 and practicing in this state with experience in treating rare diseases.	X	

Guests: Jon Conley (Florida Department of Health), Maggie Dilger (Florida Department of Health), Pradeep Bhide (Florida State University), Cynthia Vied

Call to Order, Member Roll Call – *Maggie Dilger, Florida Department of Health*

The meeting was called to order at 12:05 p.m., Roll was taken, and a quorum was established.

Approval of Meeting Minutes – *Council Members*

Dr. Barry Byrne moved to approve the minutes from the November 14, 2023, subcommittee meeting, and Dr. Rajan Wadhawan seconded. The minutes were approved.

Discussion of Subcommittee Mission – *Jon Conley, Florida Department of Health*

Jon Conley with the Department gave a brief overview of the statutory requirements of the Rare Disease Advisory Council (RDAC). He emphasized that the role of the Council was to serve those who are impacted by and those who treat rare diseases, by A) seeking ways to improve the treatment of rare diseases, and B) developing strategies for providers to better learn how to recognize and diagnose rare diseases. He explained

that Department staff would be reviewing the status of the subcommittees' objectives and seeking guidance from the subcommittees on how to continue working on those objectives moving forward.

Mr. Conley explained the three subcommittees were created by the RDAC to focus on the annual report. He asked to subcommittee to think about how often and how long the subcommittee should meet in the future to ensure the best use of the council members' time.

Dr. Byrne suggested the council meet in-person in the future and Representative Anderson and Dr. Tekin supported the idea. Mr. Conley noted the suggestion and explained there could be issues with funding an in-person meeting, but staff would research within the Department and report findings at a future meeting.

Representative Anderson sought input from both the Academic Research Institutions Subcommittee and the full council regarding strategies to enhance operational efficiencies within policy. Dr. Mustafa Tekin suggested enhancing the applicability of whole genome sequencing in diagnostics to facilitate broader diagnosis. Meanwhile, Dr. Byrne emphasized the importance of improving the accessibility of existing resources for patients and families within the state through more effective marketing strategies.

Member Updates – Council Members

No member updates were provided.

Future Agenda Items Discussion – Council Members

Dr. Byrne reiterated the desire to have an in-person meeting of the RDAC. He also suggested a presentation from the Muscular Dystrophy Association (MDA) to the full RDAC to explain how patient advocacy groups can help both on the state and national level with community engagement and legislative support. The MDA has been working on improving access to transportation options for people, particularly those with wheelchairs in airlines. Additionally, the MDA is working to help educate both patients and providers regarding gene therapies.

Public Comment

No public comment was provided.

Adjournment – Maggie Dilger, Florida Department of Health

The meeting adjourned at 12:33 p.m.